

Families as employers: Family experiences managing paid support staff

Background: There are widespread trends towards individualized funding and direct supports for individuals with intellectual disabilities and their families.

Materials and method: This study is based on qualitative interviews with families, agency managers, direct care staff, union officers, government officials, and other stakeholders in Ontario, Canada.

Results: While family experiences suggest that direct funding provides greater control and choice over the use of resources, there are significant and systemic challenges, especially in the area of human resource management. Limited funding and efforts to stretch available resources result in employment conditions and wages which are significantly lower than agency-based staff.

Conclusions: Most families choose not to manage individualized funds themselves because of the significant administrative challenges. Family experiences must be considered within the broader context of contending interests among the various stakeholders in the sector. The tensions between public policy frameworks based on consumer direction versus universal rights have a significant impact on family experiences.

Keywords: intellectual disability, family management, individualized funding

Families as employers: Family experiences managing paid support staff

Trends towards consumer directed supports and individualized funding provide people with intellectual disabilities and their families with an important mechanism for promoting greater inclusion and a higher quality of life (Lord and Hutchinson 2007). However, along with the opportunities associated with greater control over resources come critical challenges in managing those resources, especially direct support staff. Research on families in the field of intellectual disabilities has evolved into a more comprehensive, engaged, and balanced treatment of mothers, parents and families (Blacher and Mink 2004; Glidden *et al.* 1988). Such scholarship has shown that experiences of disability have both positive and negative impacts on families. Family members play a critical role in advocacy and the provision of supports to individuals with developmental disabilities. However, the role of families as the managers of paid staff providing those supports represents an important gap in the literature (Caldwell and Heller 2003). This study seeks to address that gap and analyze the experiences of families as employers, managing human resources and balancing the contending pressures of social and employment relations.

In 2004, the government of Ontario launched an initiative to further transform the developmental services sector by closing the remaining government-run institutions and strengthening community based supports (Ministry of Community and Social Services 2006). Family advocates have played a significant role in the shift from institutional care to community-based supports. More recently, families and family organizations independent from service-providing agencies have taken a more formal role in the transformation of the sector through consultations and membership on governmental advisory committees (Parsons 2006, Informant 17). Independent family organizations have been the most outspoken advocates lobbying for greater control and choice over the timing and types of supports available. These groups have

targeted individualized funding as the first choice for supporting community inclusion of individuals with developmental disabilities (Lord & Hutchinson 2003, Individualized Funding Coalition for Ontario 1998).

The prevalence of direct payments is limited in Ontario compared to other jurisdictions (Askheim 2005, Pedlar *et al.* 2000). Nevertheless, Ontario presents an interesting and dynamic case for researching family management of paid support staff under individualized funding. Direct funding through the Special Services at Home (SSAH) program has been available in Ontario since 1982. The Ontario legislature's recent passage of Bill 77, *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act 2008*, enables the government to significantly increase the prevalence of direct funding. While direct funding is intended to give families more choice and flexibility, it may also present increased challenges as families assume administrative responsibilities such as payroll and health and safety compliance as well as the recruitment, training and management of staff.

The current research project has two primary objectives. First, this study seeks to identify the types of human resource strategies and practices that families have adopted under direct funding programs in Ontario. Staff management activities include recruitment, training, retention, performance evaluation, conflict resolution and determination of wages and other terms and conditions of employment. Second, this study analyzes the challenges associated with family management of paid support staff within the context of contending interests among stakeholders in the sector and contested public policy regimes. Are the challenges minimal, suggesting that direct funding delivers the benefits of control and flexibility without significant transaction costs on the part of families? Conversely, do the experiences of families managing

staff through individualized funding reflect the devolution, privatization, and degradation of public services?

Family experiences with individualized funding in Ontario also inform the broader debates surrounding the restructuring of public services in general and the transformation of developmental services in particular. On one side of the debate, advocates for individualized funding view it as a necessary condition for the empowerment of individuals with intellectual disabilities (Lord & Hutchinson 2003, Individualized Funding Coalition of Ontario 1998, Stainton 2005). According to some family advocates (Informants 1, 2, & 17), community-based agencies have in effect become entrenched, professionalized, and bureaucratized service providers. On the other hand, critics of direct payment programs argue that direct payments reflect trends towards privatization and the degradation of public services (Kastner & Walsh 2008, Canadian Union of Public Employees 2008). The model of consumerism promoted by individualized funding, according to this line of argument, is the antithesis of universal rights (Cumella 2008).

The next section briefly examines the limited research on family experiences with consumer directed supports. The research on family managed supports also attempts to link these studies with the broader debates surrounding the public policy shifts to direct payments. The third section provides the background and context of developmental services in Ontario, tracing the restructuring process of the sector and summarizing the current state of individualized funding. The experiences of family managers and perspectives of other stakeholders on direct hire practices are presented in section four. Section five places family experiences within the context of the broader debates and contending interests concerning individualized funding. The

conclusion summarizes the key findings and raises important questions for additional research in this area.

Researching families, staff and employment relations

Research on families in the field of intellectual disabilities has evolved into a comprehensive treatment of family systems and human ecology (Bronfenbrenner 1979). Major streams within this body of research address the use of family observations for clinical assessments (Shaffer *et al.* 1999), the negative and positive impacts of disability on the family (Blacher & Hatton 2001), and the life-stages perspective on family processes (Heller *et al.* 1997). A growing stream within this broader literature considers clinical outcomes and family experiences resulting from de-institutionalization and changing models of publicly funded support (Caldwell 2007, Caldwell & Heller 2007, Stainton & Boyce 2004). Several studies of direct payment programs in the US (Caldwell 2007), the UK (Stainton & Boyce 2004, Cumella 2008), and Canada (Lord & Hutchinson 2003) provide important insights into the impacts of individualized funding on families.

Research on individualized support and consumer-directed services at home have found that such changes in the provision of developmental services resulted in higher levels of consumer satisfaction in services and greater capacity for community integration (Caldwell and Heller 2007; Caldwell and Heller 2003; Lord and Hutchison 2003; Benjamin 2001). Lord and Hutchinson (2003) argue that direct funding is fundamental to the concept of self-determination, allowing people to choose where to live and the types of activities that individualized supports would enable. Extending this logic, Caldwell and Heller (2007) find that direct funding programs in the field of developmental disabilities target the entire family unit. In this way,

direct payment programs reduce the need for institutional placement and strengthen the natural networks of family supports.

This research also provides interesting insights into family management practices and critically assesses the administrative impacts on families. The model tested by Caldwell and Heller (2003) did not find a statistically significant association between family management of staff and reported levels of caregiver burden. A negative interpretation of these findings suggests that control of resources does not decrease caregiver burdens. Conversely, given the benefits of the program in terms of improved satisfaction and community inclusion, this finding suggests that the transaction costs of administration and management are overshadowed by the benefits of direct funding. Most families in their sample hired other relatives (52.6%), while recruitment from friends and agencies were relatively equal, 36.1% and 35.1% respectively. More families experienced difficulty with staff recruitment (46%) than with annual staff turnover (35%).

Research on human resource practices in family firms (Astrachan & Kolenko 1994, Lansberg 1983, Reid & Adams 2001, Whiteside & Brown 1991) provide important insights which may be relevant to understanding some of the challenges which families face in the context of individualized funding. One important contribution from this literature suggests that family firms reflect dual systems with institutional overlap between social and employment relations.

[O]ne undeniable fact holds true for all family firms. These organizations exist on the boundaries of two qualitatively different social institutions – the family and the business. Each institution defines social relations in terms of a unique set of values, norms, and principles; each has its own distinct rules of conduct. (Lansberg 1983; 3)

The issue of human resource management is further complicated by dynamics between family managers and non-family staff. Critiques of the dual system approach (Whiteside & Brown 1991) question the assumed oppositional nature of the social and employment

relationship norms. Nevertheless, Whiteside and Brown (1991) suggest that while family management of non-family paid staff are by nature no better or worse than typical human resource practices, they are more complex because of the dual nature of the relationships.

The study of staff in the developmental services sector has found the roles of personal characteristics (Hatton *et al.* 2001), organizational behaviours (Dyer and Quine 1998; Skirrow and Hatton 2006), and management practices (Hall & Hall 2002, Hatton *et al.* 1999) have a significant impact on job satisfaction, burnout, and turnover among direct care staff. While this literature has provided important insights into the factors that contribute to stress and well-being of staff, the role of human resource strategies is less fully developed. This gap in the literature is particularly glaring when considering family management of direct care staff given the increased practice of direct funding.

There is a distinct tension surrounding the role of staff in the disability studies literature. Lord and Hutchinson (2007) found that families pursuing individualized planning and funding built creative approaches to direct support. The authors found that the role of a personal support worker in the family-based or individual-centred model differed from agency-directed supports in three distinct ways. First, the authors argued that the purpose of personal supports in family-based settings was to build a good life in the community rather than to adhere to the limitations and regulations of custodial care in a group home setting. Second, they described support as embedded in a co-creative relationship in which the person with disabilities and their network lead. Third, creativity is required to deliver supports in a way that ensures choice, control and full participation of the individual. The authors further recognize that the transformation from traditional approaches to direct support to the type of relational support described in their study may involve tensions. Lord and Hutchinson recommend (2007: 152) that a facilitator may be

needed to mediate tensions in order to resolve the power issues before they lead to a more serious dispute.

Similarly, Hulgin (2004) found that the shift to person-centred plans was associated with tensions in staff management. Agencies in her study changed the nature of work from providing a pre-programmed set of services to everyone enrolled in an agency program, to developing a plan of services and supports based upon that individual's needs, strengths, and preferences. The human resource implications of this shift are substantial, involving changes in skills, responsibilities, and attitudes towards the nature of work in the sector. Hulgin (2004) found that organizations which adopted a person-centred approach to the provision of services experienced significant turnover in staff.

For direct care staff and the unions which represent them, shifts in the provision of developmental services from the public sector to the private sector is generally associated with lower wages and fewer benefits for front line employees (Lakin *et al.* 2003; Braddock and Mitchell 1992). Previous research on restructuring of human services in Canada found that the shift towards market-oriented service provision has increased the commodification of disabilities and resulted in the degeneration of services (Pedlar and Hutchison 2000; Pedlar *et al.* 2000). Specifically, Pedlar and her colleagues (1999, 2000) found that privatization and the emergence of for-profit service providers forced all agencies within the sector to maximize revenues and lower costs. These questions also reflect political tensions between advocates for a funding model that emphasizes individual rights through consumer control versus those seeking universal coverage through citizenship entitlements.

The literature growing out of the disability rights movement argues that the control resources and services is a fundamental feature of the move towards self-determination and full

participation in the community (Lord & Hutchinson 2003). However, the enhanced benefits generated by the control of resources to hire support staff and purchase services also come with significant transaction costs, especially in the management of human resources (Canadian Union of Public Employees 2008). Furthermore, the trends toward a consumer-oriented approach may have a deleterious impact on the universal rights of inclusion and citizenship long-sought by disability advocates (Cumella 2008).

Methods

This study is part of a larger project which examines the impact of restructuring in Ontario's developmental services sector on human resource practices and labour relations. The researcher conducted ten interviews with mothers and one father regarding their family's experiences in general, and especially in managing direct support staff. Another twenty semi-structured interviews were conducted with a broad range of stakeholders in the sector, including executive directors and human resource managers of community living agencies, government officials from the Ministry of Community and Social Services (MCSS), direct support staff, and trade union officials. The interviews were conducted at locations most convenient to the participants including in the family home, at agency and union offices, and other public facilities. On average, the interviews were an hour in length, ranging from thirty minutes to nearly three hours. The interviews were digitally recorded and transcribed. The qualitative interview data were analyzed for common themes, validation of facts across informants, and for points of common interests and conflicting perspectives between research participants.

Using participant observation methods, the researcher attended eight organizational events including conferences, workshops, and meetings of the various stakeholder groups and family advocacy organizations. Documentary data were gathered from these events, the

interview participants, and organizational websites. While the qualitative nature of the study and the unique characteristics of the developmental services sector in Ontario may limit generalizability, family experiences provide important lessons for the management of direct hire staff and public policy implications. This research design, which collected data from multi-stakeholders, addressed concerns of bias in the sample of interview participants. For example, families which had the most experience with direct hiring practices under individualized funding, tended to be very active in family-run, disability rights organizations, independent from the community living agencies. These independently organized family associations have led efforts to establish and expand individualized funding, but are not representative of all families of individuals with intellectual disabilities. Data collected from managers at the community living agencies and other stakeholders, provided an important, and occasionally contrasting perspective of family responses to the challenges associated with human resource management. The lack of self-advocates as interview participants reflects a shortcoming in the research design. The role of individuals with intellectual disability in the management of paid support staff is a critical question for future research, but it is not addressed here. Instead, this study focuses on the experiences of families as human resources managers. In most cases, the parents, especially mothers (Panitch 2008), were the primary advocates, responsible for staff management and the administration of the direct funds. Generally, siblings were formally involved in the circles of support, but did not manage day-to-day supports.

The restructuring of developmental services in Ontario Canada

The government of Ontario officially began the de-institutionalization process in 1977 with the launch of the first in a series of multi-year plans to provide community living opportunities. By 1986, five of the 19 government-run institutions had closed, and the number of

residents at the remaining institutions was in decline. The MCSS announced a new transformation initiative for the developmental services sector in 2004. The government replaced the thirty-year old Developmental Services Act with the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008. Final closures of the three remaining state-run institutions took place in early 2009.

Special Services at Home (SSAH) began in 1982 as a program to support families providing care at home for their child with developmental disabilities rather than having her placed in an institution. The SSAH program provides a limited amount of funding to individuals and families to purchase services and supports directly. In 1992, the program was expanded to include children with physical disabilities and adults with developmental disabilities. The MCSS enacted additional changes in 2005 to provide supports for individuals not living at home or a ministry-funded supported residence. The second policy change allowed SSAH funds to be used to hire some relatives to provide respite and other family supports. Family participation in the program has grown substantially, especially in the past 15 years. By 2008, over 28,000 Ontario families accessed funds directly through SSAH. However, funding levels are modest, providing less than CND \$4,000 on average and capped at CND \$10,000 maximum annually. While the province budgets nearly CND \$1.5 billion for developmental services annually, only CND \$98 million flows to families directly through SSAH.

In 2005, the Ontario government launched a new initiative to support individuals transitioning from school to community through a program titled Passport. The new program provides up to CND \$25,000 in funding flowed either through existing transfer payment agencies or directly to families to purchase day supports. Passport provides support to 2,175 people

across Ontario while over 3,100 individuals were on a wait list as of November 2008 (Ministry of Community and Social Services 2008).

In addition to these two established programs, the Ontario government has funded a variety of pilot projects, small scale programs which provide funds directly to families. Generally, these projects have been the result of persistent lobbying efforts by families and advocacy organizations (Informant 2). One such project provided various levels of direct funding to ten families in the Toronto region. Families administered the funds and took responsibility for all aspects of hiring and managing support staff.

Greater control – less support: Experiences of family managers

The families in this study had a variety of motivations for seeking direct funding supports. First, the transition from an inclusive school setting to an unsupported adult setting generated real frustrations with the existing system. One family, when faced with pressure to send their young child to a segregated preschool, had moved in order to live in a school district that promoted full inclusion from kindergarten through high school graduation. While the school provided mechanisms for inclusion, that support disappeared upon graduation.

It's the toughest transition that we've gone through. It's not so much finding welcoming places for who will welcome young people with disabilities, there are lots of places and businesses in town that will do that. But again it's around financing and finding support workers to accompany the young person to be able to participate in these different businesses and opportunities. It's been difficult to find good support people to be able to pay them to have enough money. If you don't have enough money, you're out of luck. (Informant 2)

Choice in the types of services and supports was the second motivating factor for families to pursue individualized funds. Families expressed dissatisfaction with existing programs and agency-based supports which they felt did not match the interests and aspirations of their family member, or kept individuals with disabilities in segregated settings. Along with more choice and control over the types of supports and activities, families sought flexibility for greater

community inclusion and a more natural integration with the network of families and friends as well as the broader community.

The first challenge families face when they assume control of funding is the recruitment and management of staff. While recruitment and retention has been a chronic problem in the sector (Eakin & Thelander 2005, Test *et al.* 2003), agency managers reported that turnover rates were very low among full-time staff, but retention remains a concern among part-time and casual employees (Informants 7, 8, & 19). Compared to transfer payment agencies, families experience much greater challenges in these key areas of human resource management. Limited and stagnant funding levels generally require families to pay wages much lower than those offered by agencies. Families hiring staff with SSAH funds average only a few hours a week and the opportunities for full-time employment through direct funding are very limited. As a result of the difficulties with staff recruitment and retention, families lose stability in the network of supports and have been forced to retain staff with whom they were uncomfortable.

We had one situation, well more than one, but one situation where we kept somebody longer despite the fact that we felt uncomfortable with it. Partly because if we let him go, we did not have anybody left. This was when he was still living at home. But then we started seeing signs of physical abuse, you know we started seeing a lot of bruises on him all of a sudden and our son did not want to go out with him [the support worker] anymore... (Informant 17)

Families use a variety of strategies to find and recruit appropriate staff including hiring workers supplied by agencies. However, families have had mixed experiences with the recruitment of staff from agencies. In some cases in which families choose to manage their own funds, those families found that agency supplied workers were incompatible and subsequently began hiring all their workers directly. The potential for mismatch between families and agency supplied support workers occurred on two dimensions: employment and social/philosophical. Career advancement and other traditional employment opportunities in agencies are generally

absent in families using individualized funds. While some families pooled their resources in order to provide more hours for a shared support worker, limited hours presented retention problems.

I've had staff supplied by an agency and what I found was that most of them used one-on-one community experience as a steppingstone to the next job. So what happens is they send you someone who is part time staff and is next in line for a union job. (Informant 1)

Several families adjusted their recruitment strategies to take advantage of local universities where part-time hours are more attractive to full-time students. These families reported that the success of this recruitment strategy in finding excellent support workers led them to recruit exclusively from the local university. Not surprisingly, this strategy generated a predictable turnover pattern as students graduate and move on.

Limited funds and part-time hours were not the only problems that families encountered with staff supplied by a local agency. Several families reported that workers from agencies carried with them pre-conceived notions of supports which were driven by rules and regulatory compliance rather than individual outcomes and community inclusion.

We interview them, we look at their resumes. Sometimes we say no, this is not going to work. It's interesting, usually people almost always have worked at [a former provincial institution] or educated in a DSW [developmental service worker] kind of program. We say I don't think this person will work, they don't quite get it. They've been trained by the system. (Informant 17)

Families selected staff according to a particular social/philosophical profile that emphasized the individuality of their son or daughter. Rather than hiring a support worker who would approach the person with intellectual disabilities as a client, they wanted staff who would recognize the valuable contributions the individual could make to the community first, and their support needs second.

People who I hired myself, I moulded myself and my daughter moulded. The experience was they stayed to be part of her circle [of support] and some of them were moving on. One of the girls that I hired on my own, there was a real bonding, she's been a friend of the family. I think

it's about moulding and understanding of who the person is and tailoring things to that person and not come with any preconceived ideas. (Informant 1)

In this way, family management practices tended to blend the social and employment roles of support staff. Directly hired support staff became integrated into the broader social network of unpaid supports. While this is likely an unintended outcome of family management practices, no families required unpaid attendance at the individuals circle of support meetings, such outcomes were common in the families interviewed in this study.

Administrative challenges, specifically the recruitment and management of staff, emerged as the critical reason why many families chose not to manage direct payments themselves, instead, turning those over to a transfer payment agency. Agency managers reported that very few families choose to manage the individualized funds themselves.

I think a lot of people come to us with their Passport dollars because they don't want to have anything to do with the hiring and firing of staff. They want us to make sure that we hire somebody that they are well trained, and we are watching over them. Quite honestly, once you get into a position where you have people calling in sick all the time and you have to fill in or you have to stay home from work because your son or daughter is not being taken care of, then you realize it is kind of nice for somebody else to deal with it. (Informant 18)

Agencies take responsibility of managing individualized funds for families in a variety of ways. In general, these arrangements involve contractual, fee for service agreements with the families. Most families do not attempt to manage the supports themselves, preferring instead for the agency to handle the administrative details of the supports. Agencies have a much more difficult time accommodating families which seek greater control over the management of the resources, especially in the selection of staff and flexibility of hours.

For most Ontario families, the choices under individualized funding are limited to either directing those funds to a transfer payment agent, and thereby entering the 'system' of developmental service providers, or managing the funds themselves with no infrastructure for

administrative support. However, one ‘grassroots’ agency (Hulgin 2004) in Ontario was established based on the SSAH funding model, providing family supports in a way that potentially represents a hybrid model between agency-based administrative capacity and family managed supports. In effect, support staff is co-managed between the agency and the family or broader circle of supports.

Just because somebody has a child with a disability doesn’t mean that you have got all the answers. People are susceptible to self-limiting assumptions about their child’s future and you need someone from the outside to help you look at that and then about what we do about it. Where parents are into having to be businesses by hiring people and accept the responsibility that is associated with that, more power to you. But the only reason they are doing it is because they don’t have [the supportive hybrid agency] in their backyard. (Informant 3)

Limited SSAH funds negatively impact the agency which struggles to improve employment conditions where increased wages translate more explicitly and immediately into fewer hours of support. As a result, wages at this agency tend to be somewhat lower compared to traditional transfer payment agencies, and none of the direct care staff hold a full-time position. This agency provides an effective and sustainable model that helps coordinate family and related in-home supports with individualized funds, but the agency provides a very limited number of out-of-home residential supports. In part, this reflects the constraints of SSAH funds and limited direct payments for residential supports.

The problem of residential supports is structural and widespread in Ontario. The existing transfer payment agency-based system currently provides residential supports to 15,000 people in Ontario. However, over 10,200 individuals are on waiting lists and the problem is becoming more acute as parents and people with developmental disabilities age (Ministry of Community and Social Services 2008, Canadian Union of Public Employees 2008).

Limited funding and contending interests

The lack of infrastructure to support family management of direct payments reflects a critical feature of the fiscal landscape in which the transformation of the sector is taking place in Ontario. Limited resources intensify the differences of opinion and contending interests of the main stakeholders in the sector: families, agencies, unions, and government. These contending interests reflect the broader political debates over a universal rights framework versus a model based on consumer control and choice.

Not surprisingly, families would prefer to have some direct funds than be placed on a wait list (Caldwell & Heller 2003). While family organizations certainly explicitly their advocacy efforts for individualized funding on concepts of self-determination and inclusion, pragmatic efforts to achieve some measure of support in an environment of wait lists is another motivating factor. In the context of scarce resources, it is natural that families would view the relatively large budgets for agency based services and supports with frustration.

The institutional interests of the agencies would seemingly be opposed to the growth of individualized funding, but this study found very little evidence of that among agency managers. While individualized funding has the potential to eliminate transfer payment agencies in Ontario, most agency managers view this as an extremely unlikely outcome. While funds may go directly to families, much of it still flows through the agency network of services and supports. In programs which currently provide direct funding to families, SSAH and Passport, most families still ask the agency to manage the services and supports. Still, not all families want the types of supports and services offered under that traditional transfer payment agency model.

We're trying to move from the old pity model to the model where people have rights and they are citizens of Ontario and they can have some choices. I'm sorry, but the agencies are all still in the pity model and they think they're really helping us but are actually hurting us but they won't stay long enough to listen to why it's not helping us so we're still struggling. (Informant 2)

The families most active in lobbying for direct funding dismiss the notion that agencies are doing them a favour by taking over the administrative burdens. The context of limited funding also highlights the paradox of broadening direct funding programs and family desires for individualized supports. Namely, it is not clear whether there can truly be a balance between universal rights and entitlement to developmental supports on the one hand, and consumer directed funding on the other.

I was a believer that it [individualized funding] needed to be available to a broader number of people. I was also aware of the contradiction between individual funding, with flexibility and portability and all that kind of stuff, but if you give access to everybody, when you make something available to every citizen you have to move to standardization. (Informant 3)

In contrast to the relatively subdued response by agencies, labour unions in Ontario have been adamantly opposed to the expansion of individualized funding mechanisms for a variety of reasons. Unions argue that individualized funding has negative effects on the labour market outcomes of direct support professionals. The employment status of the support worker is generally not clear. Most staff hired under this arrangement are considered independent contractors and therefore not entitled to most provisions of the provincial Employment Standards Act. According to this argument, public sector restructuring in the developmental services sector is generating a race to the bottom for both the quality of life for people with disabilities and the quality of employment conditions for support staff (Informant 5). In effect, labour unions argue that the cost reduction motivations of government displaces and ultimately undermines the objective of disability rights advocates who seek a system of supports that promote community inclusion.

Conclusion

This study of family management practices has found that relatively few families choose to retain control over individualized funds. Administrative burdens, especially the challenges of

recruiting and managing staff, compel most families to essentially return the funds to the agency-based system of supports and services. Families which choose to manage the funds themselves, do so without any infrastructure for administrative supports. Their motivations for individualized funds, such as flexible supports and enhanced opportunities for community inclusion, outweigh the costs of administration. The families were seeking a fundamentally different approach to support than what they felt the agencies were offering.

Family managers are significantly constrained by the limited funds available through the direct payment programs. These constraints translate into lower wages and part-time hours for most direct hire staff. Despite these limitations, family managers reported nurturing close relationships with support staff. This feature of family management practices which overlap social and employment relations is consistent with previous research (Caldwell and Heller 2003) which found that families developed long-term, close relations with hired directly staff.

There are two critical limitations to the current study which should be pursued in future research. First, self-advocates and the role of people of with intellectual disabilities in the management of support staff requires more careful examination. Among the families interviewed in this study, people with developmental disabilities were fully included in the hiring process. Their role in the training and ‘moulding’ of staff and the blending of the social and employment relations would be a rich and important question for future research. Second, the nature of qualitative research and the dominance of interview participants who were active in independent family organizations is not representative of the population of Ontario families receiving direct funds. The larger research project will quantitatively explore the patterns of family management practices identified in this qualitative study.

Finally, this study suggests that family experiences have to be considered within the broader context of contending stakeholder interests. Efforts by labour unions to protect both agency-based jobs and the integrity of public services works against cost containment efforts by government. These contending interests reflect the tensions between a universal rights approach and individualistic consumerism. There is also a potential paradox between individualized funds and universal rights. Specifically, would full enfranchisement of individualized funds lead to the type of standardization that some families are trying to break away from? The current study raises more questions than it answers, especially regarding whether an agency-based system and individualized funding programs are compatible. It is not clear that current public policy tools can strike a balance between consumer rights and universal citizenship entitlements (Cumella 2008: 183).

References

- Askheim O. (2005) Personal assistance – direct payments or alternative public service. Does it matter for the promotion of user control? *Disability & Society* 20 (3), 247-260.
- Astrachan J. & Kolenko T. (1994) A neglected factor explaining family business success: Human resource practices. *Family Business Review* 7 (3), 251-262.
- Benjamin A. (2001) Consumer-directed services at home: A new model for persons with disabilities. *Health Affairs* 20(6): 80-95.
- Blancher J. & Hatton C. (2001) Current perspectives on family research in mental retardation. *Current Opinion in Psychiatry* 14, 477-482.
- Blancher J. & Mink I. (2004) Interviewing family members and care providers: concepts, methodologies, and cultures. *The international handbook of applied research in intellectual disabilities* (Eds. E. Emerson, C. Hatton, T. Thompson, & T. Parmenter) John Wiley & Sons Ltd., West Sussex.
- Braddock D. & Mitchell D. (1992) *Residential services and developmental disabilities in the United States: A national survey of staff compensation, turnover, and related services*. American Association on Mental Retardation, Washington DC.
- Bronfenbrenner U. (1979) *The ecology of human development: Experiments by nature and design* Harvard University Press, Boston.
- Burton M. & Kagan C. (2006) Decoding “Valuing People.” *Disability and Society* 21, 299-313.
- Caldwell J. (2007) Experiences of families with relatives with intellectual and developmental disabilities in a consumer-directed support program. *Disability & Society* 22 (6), 549-562.
- Caldwell J. & Heller T. (2003) Management of respite and personal assistance services in a consumer-directed family support programme. *Journal of Intellectual Disability Research* 47 (4/5), 352-366.
- Caldwell J. & Heller T. (2007) Longitudinal outcomes of a consumer-directed program supporting adults with developmental disabilities and their families. *Intellectual and developmental disabilities* 45 (3), 161-173.
- Canadian Union of Public Employees (2008) *CUPE Ontario submission on Bill 77, The Services for Persons with Disabilities Act*. CUPE Research, Ottawa.
- Cumella S. (2008) New Public Management and public services for people with an intellectual disability: a review of the implementation of *Valuing People* in England. *Journal of Policy and Practice in Intellectual Disabilities* 5 (3), 178-186.

- Dale S., Brown R., Phillips B., & Carlson B. (2003) *The experiences of workers hired under consumer direction in Arkansas*. Mathematica Policy Research Inc., Princeton, NJ.
- Dyer S. & Quine L. (1998) Predictors of job satisfaction and burnout among the direct care staff of a community learning disability service. *Journal of Applied Research in Intellectual Disabilities* 11(4), 320-332.
- Eakin L & Thelander M. (2005) *Beyond numbers: the implications of financial restraints and changing needs on developmental services*. Lynn Eakin and Associates, Metro Agencies Representatives Council.
- Glidden L. M., Valliere V. N. & Herbert S. L. (1988) Adopted children with mental retardation: positive family impact. *Mental Retardation* 26, 119-125.
- Hall P. & Hall N. (2002) Hiring and retaining direct-care staff: After fifty years of research, what do we know? *Mental retardation* 40 (3), 201-211.
- Hatton C., Emerson E., Rivers M., Mason H., Mason L., & Swarbrick R. (1999) Factors associated with staff stress and work satisfaction in services for people with intellectual disability. *Journal of Intellectual Disability Research* 43, 253-267.
- Hatton C., Emerson E., Rivers M., Mason H., Mason L., & Swarbrick R. (2001) Factors associated with intended staff turnover and job search behaviour in services for people with intellectual disability. *Journal of Intellectual Disability Research*. 45, 258-270.
- Heller T., Hsieh K., & Rowitz L. (1997) Maternal and paternal caregiving of persons with mental retardation across the life span. *Family Relations* 46, 407-415.
- Hulgin K. (2004) Person-centred services and organizational context: Taking stock of working conditions and their impact. *Mental Retardation* 42 (3), 169-180.
- Individualized Funding Coalition for Ontario (1998) *Individualized funding: First choice option for developmental services*. Individualized Funding Coalition for Ontario.
- Kastner T. & Walsh K. (2008) Divided we stand, united we fall: Personal budgets versus universal coverage. *Intellectual and developmental disabilities* 46 (3), 239-242.
- Lansberg I. (1983) Managing human resources in family firms: The problem of institutional overlap. *Organizational Dynamics* 12 (1), 39-46.
- Lakin K.C., Polister B., & Prouty R. (2003) Wages of non-state direct-support professionals lag far behind those of public direct-support professionals and the general workforce. *Mental Retardation* 41 (2), 141-146.

- Lord J. & Hutchison P. (2003) Individualized support and funding: building blocks for capacity building and inclusion. *Disability & Society* 18 (1), 71-86.
- Lord J. & Hutchison P. (2007) *Pathways to inclusion: Building a New Story with people and communities*. Captus Press Inc., Concord, Ontario.
- Ministry of Community and Social Services. (2006) *Opportunities and action: transforming supports for people who have a developmental disability*, Queen`s Printer for Ontario.
- Ministry of Community and Social Services. (2008) Transformation of developmental services in Ontario. Presentation at the Southeast Ontario Community-University Research Alliance Conference. Kingston, Ontario.
- Panitch M. (2008) *Disability, mothers, and organization: Accidental activists*, Routledge, New York.
- Parsons E. (2006) *Report on consultations regarding the transformation of developmental services* Parliamentary Assistant (Disabilities) to the Minister of Community and Social Services, Ontario.
- Pedlar A., Hutchison P., Arai S., & Dunn P. (2000) Community services landscape in Canada: Survey of Developmental disability agencies. *Mental Retardation* 38(4), 330-341.
- Pedlar A., & Hutchison P. (2000) Restructuring human services in Canada: commodification of disability. *Disability & Society* 15 (4), 637-651.
- Reid R. & Adams J. (2001) Human resource management – a survey of practices within family and non-family firms. *Journal of European Industrial Training* 25 (6/7), 310-320.
- Shaffer L., Lucas C., & Richters J. (Eds) (1999) *Diagnostic assessment in child and adolescent psychopathology*, Guilford, New York.
- Skirrow P. & Hatton C. (2006) Burnout amongst direct care workers in services for adults with intellectual disabilities: A systematic review of research findings and initial normative data. *Journal of Applied Research in Intellectual Disabilities* 20, 131-144.
- Stainton T. (2005) Empowerment and the architecture of rights based social policy. *Journal of Intellectual Disabilities* 9, 289-298.
- Stainton T. & Boyce S. (2004) ‘I have got my life back’: Users’ experience of direct payments. *Disability & Society* 19 (5), 443-454.
- Test D., Flowers C., Hewitt A., & Solow J. (2003) Statewide study of the direct support staff workforce. *Mental Retardation* 41 (4), 276-285.

Torjman S. (November 1996) *Dollars for Services: a.k.a. Individualized Funding*, Caledon Institute of Social Policy.

Whiteside M. & Brown F. (1991) Drawbacks of a dual systems approach to family firms: Can we expand our thinking? *Family Business Review* 4 (4), 383-395.